

**THE ADHERENCE BOND
TRANSFORMATION OF A DEAF MOTHER WITH AIDS**

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The Adherence Bond: Transformation of a Deaf Mother with AIDS

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Virologic suppression is undoubtedly associated with adherence to antiretroviral therapy. Studies have demonstrated this association through measurement of plasma HIV RNA levels, CD4 cell counts, and mortality rates in patients who have been electronically monitored through microchips in their medication bottle caps. Levels of $> \text{ or } = 95\%$ are required to maintain virologic suppression, yet most studies show that 40-60% of patients are $< 90\%$ adherent.(1) According to Monreal et al, adherence can be influenced by the characteristics of the therapeutic program, by health care providers, by the patient, and by society in general.(2) Many reasons are given for nonadherence in countless studies; from loss or misplacement of medicine (1) to scheduling problems (ie, being away from home, too busy, change in daily routine).(1,4) Early in my practice I was fortunate to have a patient who taught me about adherence and taught herself how to live.

J is a 36-year-old African American deaf woman I met in 2003. She was referred to me by the pharmacist in our clinic. She had not been in to get her medication in over 6 months and had not been to the doctor in over a year. I discovered her CD4 had fallen below 200 cells/ μL even though her VL remained undetectable. Prior attempts to schedule a visit had failed. A letter was written by the case manager to schedule a routine Pap smear. As a Nurse Practitioner, my role was to provide primary care. Adherence bonding begins with teamwork, and the bond can be initiated by any member who identifies an adherence problem.

J responded to the letter by coming in because she was bothered with a relatively minor opportunistic infection. It gave me an opportunity to establish a primary care role with her and to gain trust. Primary care providers (PCPs) offer many nonthreatening opportunities for screening and bonding with patients on non-HIV visits and can establish a comprehensive relationship, giving patients an opportunity to focus on more than numbers and HIV symptoms and medication side effects.

J was deaf and partially mute. She had not been to the clinic because she felt intimidated by the difficulty others had with her disability. I understood this feeling well having a hearing loss myself. J and I connected on this level when I showed her my hearing aids and used sign language to communicate with her. I read lips very well and she taught me signs I didn't know. J also had a deaf daughter so she was fluent in American Sign Language, having learned it at the Deaf Action Center, a United Way agency in our community. Medical indigence precluded her filling a prescription for hearing aids written in prior years that would have cost her \$3,000 to \$5000. She was eligible for a Teletype Phone System at no cost, however. Given the time and opportunity, she enjoyed looking at the computer when she came into the clinic. This is how she learned about her lab results and the meaning of her viral load and CD4 count and how her medication affected them. Our case manager was also able to use the computer in helping her find resources for paying for hearing aids for herself. Charts, books, my own written instructions, and diagrams helped to augment treatment planning. I encouraged other staff to use alternative forms of communication. Usually translators are available through the Deaf Action Center at a cost of \$60.00 per hour. The clinic is responsible for this cost as a provision of the Americans with Disabilities Act. Patients with sensory deficits require more time and that time must be scheduled. We, the providers of health care, are generally inept at speaking their language. It is our responsibility to meet their needs rather than the other way around. At our clinic, we are now fortunate to have a bilingual nurse who speaks both English and American Sign Language (ASL). In 2003 we had to struggle to communicate the best way we knew how. As limited as I was in my "pigeon" sign

language in 2003, J continued to keep coming back until she became adherent and resolved her opportunistic infections. Her CD4 finally became stable once again. When questioned what she owed this change in adherence to she responded that her attitude changed as a result of having someone to “talk” to.

J’s first regimen was Combivir and Crixivan started in 1996. It was changed when Trizivir came out to improve adherence. The one tablet bid regimen was helpful in improving her adherence but she eventually forgot that second dose and then her virus developed mutations. It is surprising that the VL stayed undetectable while the genotype and phenotype showed resistance. The CD4 however fell from the mid 200s to a nadir of 145. J was quick to understand this when the appropriate metaphors were used to explain using labeled drawings. The metaphor I used to explain pathogenesis and pharmacotherapeutics is one I call “The Safe House.” I believe the metaphor speaks to patients in our population who are from high risk neighborhoods. The house is a representation of the host CD4 cell. It is described as safe as long as ARVs (HIV medicines) guard the doors – front, back, and side. There are 3 doors to represent the classes of drugs which must be combined to form the composite strength of the regimen to prevent resistance. The loss of one “guard” will render the house “unsafe.”

J began to understand how the numbers were affected and began to see the effects of adherence by coming in and looking at the computer herself to evaluate her own results. Eventually she was open to going back to the case manager to find resources for funding to get hearing aids. Even though she was functional in her deaf world, it was small and she yearned to go beyond it. She received hearing aids which added to her self-sufficiency and this showed her a new world. She registered for school. She began to think more of herself. She began to stay in contact with her case manager at the community-based organization. I was amazed at the change.

I continued to monitor lab results and update treatment as needed. The successful regimen she is on today is Viread, Zerit, and Sustiva. She has had no problems with it and has continued to be adherent for lab visits and medications. She has retained immune stability and showed no further opportunistic infections to date. She has not been as consistent about clinic visits.

For an HIV treatment plan to be successful it must be simple, written down, and tailored to the patient’s lifestyle. Few HIV/AIDS patients speak in the acronyms or medical terminology of the language we take for granted. In fact most patients are emotionally deafened by it. Imagine how confused we might be in some of our patient’s cultures be they gay, African American, rural southern Caucasian, or urban Junior League.

It is impossible for one member of a health care team to develop and implement comprehensive treatment plans for a patient with multiple medical and social problems. The more support a patient receives for virologic suppression through adherence, the more likely they are to recall the message. Someone else with a different discipline may have a more effective message. I often refer to the dietitian to head off cholesterol or blood sugar problems. She/he can even help patients comply with food boosting especially if they have erratic eating habits such as sleeping late and not eating until mid day. J was an obese and depressed patient who got up at 4 am to go to work in a fast food restaurant. This may have contributed to side effects. Dieticians are accustomed to dealing with nonadherence and addictive disorders and are trained to individualize food plans.

Treatment of depression can facilitate adherence. Sensory impairment compounds the isolation of HIV/AIDS resulting in chronic depression or grief that the patient may think is a normal state. Upon inquiry, depression will often be denied. However, most patients will acknowledge fear that can often be paralytic. Even patients without sensory impairment have anxiety accompanied by a kind of an emotional deafness. This may put them in a “zone” unable to respond appropriately or recall information. Sometimes repetition, visual aids, referrals to other team members especially for substance abuse, and treatment of anxiety as a manifestation of depression are in order for the “emotionally deaf.” Buspirone works well for anxiety especially in connection with SSRIs.

If a cycle of chronic pain and substance abuse have brought about nonadherence, it may be overlooked by providers

who may assume that the patient is making a conscious choice to self-medicate with illegal drugs. Early in substance abuse, this may be the case. However, every addict crosses a line where conscious choice is no longer an option. Addiction is a disease over which patients have no power or choice. It is a legal imperative that providers document the recommendation of substance abuse treatment not only to the patient who is almost guaranteed to refuse it as denial is part of the disease, but also to a close family member or friend who might participate in a professional intervention. Pain management should be offered also along with substance abuse treatment whether the patient agrees to terms or not. Most pain clinics will have patients sign a contract and conduct drug screens. Left to their own devices, addicts will titrate their “pain medication” to lethal doses inadvertently. I have learned from pain clinics that many agents including gabapentin can be compounded with ketoprofen, cyclobenzaprine, or even ketamine to accomplish astounding pain relief topically. This can work well with the addict or liver failure patient.

I believe encouragement is empowerment. I try to celebrate progress and accomplishments always acknowledging efforts where they are made. Integrity is the keystone of the adherence bond and this is where respect is built. Upholding the treatment plan is demonstrating integrity. I believe the bond is reinforced when integrity is identified in the patient, especially where it has been lacking. I think it is just as important to ask why someone has become adherent as to probe the reasons for nonadherence. Perhaps it is more important. The adherent person is more in touch with the rational self. The nonadherent person is often not sure of what his/her rationale is. It may be first one thing and then another -- or chaos in general. I like to think the big picture for everyone is a self-portrait of themselves in harmony with the universe.

The man or woman in chaos needs a rational voice (or in J’s case silent hands) who affirms his or her ability to make decisions. He/she does not need someone else to make decisions or to bully or intimidate him/her into doing what a medical provider wants, but rather needs to feel a part of something good. When all is said and done, in adherence bonding we render a spiritual dimension of care. We are caring for souls as well as bodies in addressing adherence. Within the soul there lies the capacity for great mystery and great paradox. Thomas Moore writes, “Every fall into ignorance and confusion is an opportunity to discover that the beast residing at the center of the labyrinth is also an angel. The uniqueness of... a person is made of the insane and twisted as much as it is of the rational and normal. We must care for suffering with extreme reverence so that in our fear and anger at the beast, we do not overlook the star.”(3) This references a potential transformation within each nonadherent soul. Therein lays the hope that keeps my practice from the edge of burn-out.

The responsibility we have in maintaining the bond is fraught with pitfalls and tendencies to enable, whine, point fingers, pass the buck, judge, argue, manipulate, and even abandon these difficult patients. I have had to remind myself of the rights that I have as a provider when I am pushed to the limit.

1. Let go in an existential sense.
2. Detach from the outcome in an emotional sense and accept what I cannot change. This doesn’t mean I do not care.
3. Consult/share my concerns, especially if there is an NP/Physician Collaborative relationship.
4. Be disappointed.
5. Contact Child Protection Services in cases of neglected and abandoned children.
6. Call the Coroner in cases of high index of suspicion or a threat for direct harm to self or others.
7. Discontinue medication and medication delivery services when regimens are not being followed properly. No HAART is better than partial HAART.
8. Report cases of felony transmission of HIV to police.
9. Report pregnant patients with adherence issues to Public Health authorities.
10. Refer for Direct Observation Therapy in cases of tuberculosis.

J has affirmed what I had been taught when I first started working at the Viral Disease Clinic. I cannot decide life choices for someone else and treatment of HIV/AIDS is trial and error. I can, however, make a difference, and mutual effort makes for quality of life.

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